CABINET FOR HEALTH SERVICES

Commission for Children with Special Health Care Needs

Health and Development Division

(Amendment)

911 KAR 2:120. Kentucky Early Intervention Program evaluation and eligibility.

RELATES TO: 34 CFR 303, 20 USC 1471-1485

STATUTORY AUTHORITY: KRS 194A.030(7), 194A.050, 200.650-676, 34 CFR 303.322, 20 USC 1473

NECESSITY, FUNCTION, AND CONFORMITY: The Cabinet for Health Services is directed by KRS 200.650 to 200.676 to administer [~~all~~] funds appropriated to implement provisions, to enter into contracts with service providers, and to promulgate administrative regulations. This administrative regulation establishes [~~sets forth~~] the provisions for evaluation and eligibility policies pertaining to First Steps, Kentucky's Early Intervention Program.

Section 1. Evaluation. (1) A child referred to the First Steps Program shall be initially evaluated to determine eligibility. Until exiting the program and in accordance with subsection (8) of this Section, the child shall be evaluated on an annual basis to determine ongoing eligibility and to evaluate progress while in the program.

(2)(a) A determination of initial eligibility pursuant to Section 2 of this administrative regulation, assessments in the identified area of delay, in accordance with 911 KAR 2:130, and the initial IFSP team meeting [~~Every child shall have an evaluation to~~

~~determine eligibility:~~

~~(a) A primary evaluation~~] shall occur within forty-five (45) calendar days after a point of entry receives an initial [~~receipt of the~~] referral; or

(b) If a determination of initial eligibility, assessments and initial IFSP team meeting [~~primary evaluation~~] does not occur within forty-five (45) calendar days due to illness of the child or a request by the parent, the delay circumstances shall be documented.

(c) If [~~When~~] a family is referred for a determination of initial eligibility [~~evaluation by the initial service coordinator~~] and the family is under court order or a social services directive to enroll their child in First Steps, the court or social service agency shall be informed within three (3) working days by the initial service coordinator, if the family refuses the determination of eligibility [~~evaluation~~].

(3) [~~(d)~~] Child records of evaluations transferred from an in-state or out-of-state developmental evaluator [~~out-of-state tertiary or developmental evaluation centers~~] shall be reviewed by the initial service coordinator and shall be utilized for eligibility determination if [~~when~~]:

(a) [~~1.~~] The records meet First Steps evaluation time lines established in subsection (4)(a) of this section; and

(b) [~~2.~~] The records contain the [~~all~~] developmental evaluation information established in subsection (10)(a) and (b) of this section [~~required by First Steps to determine eligibility~~].

(4) [~~(2)~~] The primary level evaluation is the first level in the First Steps evaluation system that shall be utilized to determine eligibility, developmental status and recommendations for further assessment to determine program planning. [~~:~~]

(a) If there is a previous [~~The~~] primary level evaluation available, it shall be used to determine eligibility if [~~is used when there are no existing evaluations available~~]~~within the allowed time limits~~]:

1. For children under twelve (12) months of age, the evaluation was [~~evaluations shall have been~~] performed within three (3) months prior to referral to First Steps; or

2. For children twelve (12) months to three (3) years of age, the evaluation was [~~evaluation must have been~~] performed within six (6) months prior to referral to First Steps; and

3. There is no additional information or the family has not expressed new concerns that would render the previous evaluation no longer valid.

(b) If there is a previous primary level evaluation available that was performed within the timeframes established in subparagraphs 1 or 2 of this paragraph but there are new concerns that shall render the evaluation no longer valid, the initial service coordinator shall request a new primary level evaluation.

(c) [~~(b)~~] Primary level evaluations shall provide evaluation in the [~~all~~] five (5) developmental areas identified in Section 2(1)(c)1. through 5. of this administrative regulation using norm-referenced standardized instruments that provide a score in the total domain for the five (5) areas;

(d) [~~(c)~~] The primary level evaluation shall be provided by a [~~team consisting of a~~] physician or nurse practitioner and a primary evaluator approved by the cabinet;

(e) A primary level [~~(d) Primary~~] evaluation shall [~~be multidisciplinary and shall minimally~~] include:

1. A medical component completed by a physician or a nurse practitioner that shall

include [~~includes~~]:

a. A history and physical examination;

b. A hearing and vision screening; and

c. A child's medical evaluation that shall be current in accordance with the EPSDT periodicity schedule. [~~according to the following:~~

~~(i) For children under twelve (12) months of age, the medical evaluation shall have been performed within three (3) months prior to referral to First Steps; and~~

~~(ii) For children twelve (12) months to three (3) years of age, the medical evaluation shall be performed within six (6) months prior to referral;~~]

2. A developmental component completed by a cabinet-approved [~~a qualified~~] primary level evaluator that utilizes norm-referenced standardized instruments, [~~measures and~~] the results of which shall:

a. Include the recommendation of a determination of eligibility or possible referral for a record review; and

b. Interpreted to the family prior to the discussion established in subsection (5) of this section [~~IFSP team meeting~~].

(f) An initial primary level evaluation shall not be performed if a child has an established risk diagnosis established in Section 2(1)(c) of this administration.

(5) Prior to the initial IFSP team meeting the initial service coordinator shall:

(a) Contact the family and primary level evaluator to discuss the child's eligibility in accordance with subsection (4)(e)2.b. of this Section. If the child is determined eligible, the team shall:

1. Make appropriate arrangements to select a primary service coordinator;

2. Arrange assessments in the areas identified in Section 2(1)(c) found to be delayed; and

3. Assist the family in selecting service providers in accordance with 911 KAR 2:110. If the child is receiving therapeutic services from a provider outside of the First Steps Program, the service coordinator shall:

a. Invite the current provider to be a part of the IFSP team;

b. Request that the provider supply the team with his assessment and progress reports; and

c. Have the First Steps provider of the same discipline consult with the current provider; and

(b) If the child is determined not eligible, the team shall discuss available community resources, such as EPSDT, CCSHCN's Title V programs, and other third-party payors.

(6) At the initial IFSP team meeting the IFSP team shall:

(a) Include the following members:

1. The parent of the child;

2. The initial service coordinator;

3. The primary service coordinator;

4. A provider who performed an assessment on the child;

5. A First Steps provider who shall provide therapeutic intervention;

(b) Verify the child's eligibility;

(c) Review the evaluation information identified in subsection (4) of this section;

(d) Review the assessment reports in accordance with 911 KAR 2:130;

(e) Determine the family's outcomes, strategies and activities to meet those outcomes; and

(f) Determine the services the child shall receive in order for the family to learn the strategies and activities identified on the IFSP.

(7)(a) [~~(3) Verification of a child's eligibility for services shall be based upon the review by parents and professionals at the initial IFSP meeting; (4)~~] Reevaluations shall be provided if the IFSP team determines [~~when~~] a child's eligibility warrants review.

(b) Primary level reevaluations shall not be used to:

1. Address concerns that are medical in nature; or

2. Provide periodic, ongoing follow-up services for post testing or testing for transition. [~~or a new condition is suspected or becomes apparent;~~

~~(a) The need for reevaluation is determined by the IFSP team;~~

~~(b) Reevaluations shall be obtained at the level of evaluation determined to be needed by the IFSP team.~~]

(c) Based on the result of the reevaluation or annual evaluation, the IFSP team shall:

1. Continue with the same level of services; [~~or~~]

2. Continue with modified services; or

3. Transition [~~Graduate~~] the child from First Steps services [~~because child is developmentally age-appropriate; or~~

~~4. Continue eligibility with a tracking and maintenance approach and reevaluate in six (6) months~~].

(8)(a) In accordance with KRS 200.664(7), in order to determine ongoing eligibility,

a developmental evaluation shall be performed on an annual basis in the anniversary month of:

1. A child's primary level evaluation; or

2. The month he was referred to First Steps if the child was determined eligible due to an established risk condition.

(b) The annual evaluation shall be performed by a primary level evaluator who is not currently providing a therapeutic intervention for that child and shall provide an evaluation in the five (5) developmental areas identified in Section 2(1)(c) of this administrative regulation.

(c) If the results of the evaluation do not meet the eligibility requirements of Section 2(1)(d) of this administrative regulation, the child shall be discharged from the program.

(9) A review of the child's First Steps record shall be [~~(5) An intensive evaluation is~~] the second level in the First Steps evaluation system that shall be utilized to determine eligibility, medical or mental diagnosis, program planning, or plan evaluation. [~~:~~]

(a) Upon obtaining a written consent by the parent, a service coordinator shall submit a child's record to the CCSHCN for a record review if [~~A child shall be referred for an intensive level evaluation when~~]:

1. A primary evaluator identifies a need for further developmental testing necessary to clarify a diagnosis to further define the child's developmental status in terms of a child's strengths and areas of need; [~~or~~]

2. A child does not [~~doesn't~~] meet eligibility guidelines at the primary level, but an IFSP team member and [~~a primary evaluator or~~] the family still have concerns that the child is developing atypically and a determination of eligibility based on professional

judgment is needed; or

3. The IFSP team requests an intensive level [~~team~~] evaluation for the purposes of obtaining a medical [~~a~~] diagnosis or to make specific program planning and evaluation recommendations for the individual child.

(b)1. If a service coordinator sends a child's record for a record review, the following shall be submitted to the Record Review Committee, Louisville CCSHCN office at 982 Eastern Parkway, Louisville, Kentucky 40217:

a. A cover letter from the service coordinator or primary evaluator justifying the referral for a record review;

b. Primary level evaluation information specified in subsection (10) of this section;

c. Available assessment reports required in 911 KAR 2:130;

d. Available IFSPs and amendments;

e. Most recent progress reports from the IFSP team members. Reports older than three (3) months shall include an addendum reflecting current progress; and

f. If requesting a record review for a child who is receiving speech therapy, a hearing evaluation performed by an audiologist within six (6) months of the request.

2. The service coordinator or primary evaluator requesting the record review shall attempt to procure and submit the following information, if available:

a. Birth records, if neonatal or perinatal complications occurred;

b. General pediatric records from the primary pediatrician;

c. Medical records from hospitalizations; and

d. Records from medical subspecialty consultations, such as neurology, orthopedic, gastroenterology or ophthalmology.

(c)1. Upon receiving a referral, a team of CCSHCN professional staff shall conduct a record review.

2. After conducting the record review, CCSHCN staff shall:

a.(i) Determine that there are at least sixty (60) calendar days from the date of the review before the child turns three (3) years of age;

(ii) Determine that further developmental testing, diagnostics or additional professional judgment are required in order to adequately ascertain the child's developmental needs; and

(iii) Refer the child for an intensive level evaluation, the third level in the First Steps evaluation system; or

b.(i) Determine that there are not at least sixty (60) calendar days from the date of the review before the child turns three (3) years of age; and

(ii) Provide the IFSP team with recommendation for transition planning;

c. Determine that the child meets or does not meet the eligibility criteria established in Section 2(1) of this administrative regulation; or

d. Provide the IFSP team with recommendations for service planning.

(d) Upon request of the CCSHCN, a team approved by the CCSHCN and consisting of the following members shall perform an intensive level evaluation: [~~A record review shall be done by an intensive team at the request of the IFSP team whenever:~~

~~1. There is a question of eligibility;~~

~~2. Concern for a child's condition; or~~

~~3. Effectiveness of a child's program plan.~~

~~(c) an intensive level evaluation shall be provided by an approved team consisting of~~]:

1. A board certified developmental pediatrician; [~~or~~]

2. A pediatrician who has experience in the area of early childhood development; [~~and~~]

3. A pediatric physiatrist; or

4. A pediatric neurologist; and

5.a. One (1) or more [~~qualified~~] developmental professionals identified in 911 KAR 2:150, Section 1; or

b. If an IFSP is currently in place, a developmental professional representing each discipline that is currently on the IFSP in addition to a professional whose scope of work addresses additional concerns expresses by the Intensive Level Evaluation team.

(10) [~~(6)~~] Family rights shall [~~must~~] be respected and procedural safeguards followed in providing evaluation services:

(a) Written parental consent shall be obtained before conducting an evaluation or assessment by the evaluator or assessor respectively.

(b) If a parent or guardian refuses to allow a child to undergo a physical or medical examination for eligibility because of religious beliefs:

1. Documentation shall be obtained in the form of a notarized statement. The notarized statement shall be signed by the parent or guardian to the effect that the physical examination or evaluation is in conflict with the practice of a recognized church or religious denomination to which they belong.

2. If a child is determined [~~With the presence of a professional judgment of~~

~~developmental delay that determines the child~~] to be eligible, First Steps shall provide, at the parent's request, services that do not require, by statute, proper physical or medical evaluations.

3. The initial service coordinator shall explain to the family that refusal due to religious beliefs may result in a denial of services which require a medical assessment on which to base treatment protocols.

(11) [~~(7)~~] A written report shall be completed upon completion of an evaluation [~~for every level of evaluation including record reviews~~].

(a) A record review report shall include the components specified in this paragraph that can be addressed without having the child or parent present for the evaluation. A report resulting from a primary level evaluation or an intensive level evaluation shall include the following components [~~The minimum components are~~]:

1. Date of evaluation;

2. Names of evaluators and those present during the evaluation, professional degree, and discipline;

3. The setting of the evaluation;

4. [~~2.~~] Name and telephone number of contact person;

5. [~~3.~~] Identifying information that includes the:

a. Child's CBIS identification number;

b. Child's name and address;

c. Child's chronological age (and gestational age, if prematurely born) at the time of the evaluation;

d. Health of the child during the evaluation;

e. [~~Age;~~

~~b.~~] Date of birth;

f. [~~c.~~] Date of evaluation;

[~~d. Evaluator's affiliation, and professional degree;~~]

g. [~~e.~~] Referral source; and

h. [~~f.~~] Reason for referral or presenting problems.

6. [~~4.~~] Tests administered or evaluation procedures utilized and purpose of instrument. No one (1) method of evaluation shall be used, but a combination of tests and methods shall be used;

7. [~~5.~~] Test results and interpretation of strengths [~~strength~~] and needs of the child;

8. [~~6.~~] Test results reported in standard deviation [~~or developmental quotient when such instrumentation is required~~] pursuant to subsection (4)(e)2 of this section;

9. Factors that may have influenced test conclusions;

10. [~~7.~~] Eligibility;

11. [~~8.~~] Developmental status or diagnosis;

[~~9. Program plan recommendations~~];

12. Suggestions regarding how services may be provided in a natural environment that address the child's holistic needs based on the evaluation;

13. Parent's assessment of the child's performance in comparison to abilities demonstrated by the child in more familiar circumstances;

14. [~~10.~~] A narrative description of the [~~all~~] five (5) areas of a child's developmental status;

15. Social history;

16. Progress reports, if any, on the submitted information; and

17. Documentation that results of the evaluation were discussed with the child's parent.

(b) The [~~full~~] report established in paragraph (a) of this subsection shall be written in clear, concise language that is easily understood by the family.

(c)1. The reports and notification of need for further evaluation shall be made available to the current IFSP team and family within fourteen (14) calendar [~~ten (10) working~~] days from the date the evaluator received the complete evaluation referral [~~was completed~~].

2. In addition to the requirements established in this Section, an intensive level evaluation site shall:

a. Provide to the Record Review Committee a copy of an evaluation report within fourteen (14) calendar days from the date the evaluator received the evaluation referral;

b. If an IFSP is currently in place:

(i) Focus recommendations on areas that are specified on the IFSP as being of concern to the family;

(ii) Identify strategies and activities that would help achieve the outcomes identified on the IFSP; and

(iii) Provide suggestions for the discipline most appropriate to transfer the therapeutic skills to the parents.

3. If it is not possible to provide the report and notification required in this paragraph by the established time frame due to illness of the child or a request by the parent, the delay circumstances shall be documented. [~~(8) Child records of timely~~

~~evaluations transferred from out of state tertiary centers or developmental evaluation centers may be utilized for eligibility determination;~~

~~(a) These records shall be reviewed for all required evaluation record components by the POE services coordinator;~~

~~(b) If information is unattainable, the child shall be evaluated for eligibility.]~~

Section 2. Eligibility. (1) A child shall be [~~Children who are~~] eligible for First Steps services if he is:

(a) Aged [~~include those who are ages~~] birth through two (2) years; [~~, and:~~]

(b) A resident of Kentucky at the time of referral and while receiving a service;

(c) Through the evaluation process [~~(a) By using appropriate diagnostic instruments and procedures, or professional judgment, are~~] determined to have fallen significantly behind developmental norms in the following skill areas:

1. Total cognitive development;

2. Total communication area through speech and language development, which shall include expressive and receptive;

3. Total physical development including vision and hearing;

4. Total social and emotional development; or

5. Total adaptive skills development; and

(d) Is [~~(b) Are~~] significantly behind in developmental norms as evidenced by the following criteria:

1. Two (2) standard deviations below the mean in one (1) skill area;

[~~(developmental quotient equivalent seventy (70) percent or below); or~~]

2. At least one and one-half (1 1/2) standard deviations below the mean in two (2)

skill areas; or

3.a. If a norm-referenced testing reveals a delay in one (1) of the five (5) skill areas but does not meet eligibility criteria, a more in-depth standardized test in that area of development may be requested if the following is evident:

(i) The primary level evaluator, service coordinator or the family has a concern or suspects that the child's delay may be greater than the testing revealed;

(ii) A more sensitive norm-referenced test tool may reveal a standardized score which would meet eligibility criteria; and

(iii) There is one (1) area of development that is of concern.

b. Upon completion of the testing established in subparagraph 1. of this paragraph, the results and information identified in Section 1(8)(b) of this administration shall be submitted by the service coordinator to the Record Review Team for a determination of eligibility;

(e) Is being cared for by a neonatal follow-up program and its staff determine that the child meets the eligibility requirements established in paragraphs (a) through (d) or (f) of this subsection; or

(f) Meets the criteria established in KRS 200.654(10)(b) who has one (1) of the following conditions diagnosed by a physician or advanced registered nurse practitioner (ARNP):

Aase-Smith syndrome	Acro-Fronto-Facio-Nasal Dysostosis
Aase syndrome	Adrenoleukodystrophy
Acrocallosal syndrome	Agenesis of the Corpus Callosum
Acrodysostosis	Agyria

Aicardi syndrome	Bixler syndrome
Alexander's Disease	Blackfan-Diamond syndrome
Alper's syndrome	Bobble Head Doll syndrome
Amelia	Borjeson-Forssman-Lehmann syndrome
Angelman syndrome	Brachial Plexopathy
Aniridia	Brancio-Oto-Renal (BOR) syndrome
Anophthalmia/Microphthalmia	Campomelic Dysplasia
Antley-Bixler syndrome	Canavan Disease
Apert syndrome	Carbohydrate Deficient Glycoprotein syndrome
Arachnoid cyst with neuro-developmental delay	Cardio-Facio-Cutaneous syndrome
Arhinencephaly	Carpenter syndrome
Arthrogryposis	Cataracts - Congenital
Ataxia	Caudal Dysplasia
Atelosteogenesis	Cerebro-Costo-Mandibular syndrome
Autism	Cerebellar Aplasia/Hypoplasia/Degeneration
Baller-Gerold syndrome	
Bannayan-Riley-Ruvalcaba syndrome	Cerebral Atrophy
Bardet-Biedl syndrome	Cerebral Palsy
Bartsocas-Papas syndrome	Cerebro-oculo-facial-skeletal syndrome
Beals syndrome (congenital contractural arachnodactyly)	CHARGE Association
	Chediak Higashi syndrome
Biotinidase Deficiency	Chondrodysplasia Punctata

Christian syndrome
Chromosome Abnormality a. unbalanced numerical (autosomal) b. numerical trisomy (chromosomes 1-22) c. sex chromosomes XXX; XXXX; XXXXX;XXXY; XXXXY
CNS Aneurysm with Neuro-Developmental Delay
CNS Tumor with Neuro Developmental Delay
Cockayne syndrome
Coffin Lowry syndrome
Coffin Siris sydrome
Cohen syndrome
Cone Dystrophy
Congenital Cytomegalovirus
Congenital Herpes
Congenital Rubella
Congenital Syphilis
Congenital Toxoplasmosis
Cortical Blindness
Costello syndrome
Cri du chat syndrome

Cryptophthalmos
Cutis Laxa
Cytochrome-c Oxidase Deficiency
Dandy Walker syndrome
DeBarsy syndrome
DeBuquois syndrome
Dejerine-Sottas syndrome
DeLange syndrome
DeSanctis-Cacchione syndrome
Diastrophic Dysplasia
DiGeorge syndrome (22q11.2 deletion)
Distal Arthrogryrosis
Donohue syndrome
Down syndrome
Dubowitz syndrome
Dyggve Melchor-Clausen syndrome
Dyssegmental Dysplasia
Dystonia
EEC (Ectrodactyly-ectodermal dysplasia-clefting) syndrome
Encephalocele
Encephalo-Cranio-Cutaneous syndrome
Encephalomalacia

Exencephaly
Facio-Auriculo-Radial dysplasia
Facio-Cardio-Renal (Eastman-Bixler) syndrome
Familial Dysautonomia (Riley-Day syndrome)
Fanconi Anemia
Farber syndrome
Fatty Acid Oxidation Disorder (SCAD, ICAD, LCHAD)
Femoral Hypoplasia
Fetal Alcohol syndrome/Effects
Fetal Dyskinesia
Fetal Hydantoin syndrome
Fetal Valproate syndrome
Fetal Varicella syndrome
FG syndrome
Fibrochondrogenesis
Floating Harbor syndrome
Fragile X syndrome
Fretman-Sheldon (Whistling Facies) syndrome
Fryns syndrome

Fucosidosis
Glaucoma - Congenital
Glutaric Aciduria Type I and II
Glycogen Storage Disease
Goldberg-Shprintzen syndrome
Grebe syndrome
Hallermann-Streiff syndrome
Hays-Wells syndrome
Head Trauma with Neurological Sequelae/Developmental Delay
Hearing Loss (Bilateral permanent hearing loss with pure tone average of 30dB or greater)
Hemimegalencephaly
Hemiplegia/Hemiparesis
Hemorrhage-Intraventricular Grade III, IV
Hereditary Sensory & Autonomic Neuropathy
Hereditary Sensory Motor Neuropathy (Charcot Marie Tooth Disease)
Herrmann syndrome
Heterotopias
Holoprosencephaly (Aprosencephaly

Holt-Oram syndrome	Kenny-Caffey syndrome
Homocystinuria	Klee Blattschadel
Hunter syndrome (MPSII)	Klippel-Feil Sequence
Huntington Disease	Landau-Kleffner syndrome
Hurler syndrome (MPSI)	Lange-Nielsen syndrome
Hyalanosis	Langer Giedion syndrome
Hydranencephaly	Larsen syndrome
Hydrocephalus	Laurin-Sandrow syndrome
Hyperpipecolic Acidema	Leber's Amaurosis
Hypomelanosis of ITO	Legal blindness (bilateral visual acuity of 20/200 or worse corrected vision in better eye)
Hypophosphotasia-Infantile	
Hypoxic Ischemic encephalopathy	
I-Cell (mucolpidosis II) Disease	Leigh Disease
Incontinentia Pigmenti	Lennox-Gastaut syndrome
Infantile spasms	Lenz Majewski syndrome
Ininencephaly	Lenz Microophthalmia syndrome
Isovaleric Acidemia	Levy-Hollister (LADD) syndrome
Jarcho-Levin syndrome	Lesch-Nyhan syndrome
Jervell syndrome	Leukodystrophy
Johanson-Blizzard syndrome	Lissencephaly
Joubert syndrome	Lowe syndrome
Kabuki syndrome	Lowry-Maclean syndrome
KBG syndrome	Maffucci syndrome

Mannosidosis	Moya-Moya Disease
Maple Syrup Urine Disease	Mucolipidosis II, III
Marden Walker syndrome	Multiple congenital anomalies (major organ birth defects)
Marshall syndrome	
Marshall-Smith syndrome	Multiple Pterygium syndrome
Maroteaux-Lamy syndrome (MPS VI)	Muscular Dystrophy
Maternal PKU Effects	Myasthenia Gravis - Congenital
Megalencephaly	Myelocystocele
MELAS	Myopathy - Congenital
Meningocele (cervical)	Myotonic Dystrophy
MERRF	Nager (Acrofacial Dysostosis) syndrome
Metachromatic Leukodystrophy	Nance Horan syndrome
Metatropic Dysplasia	NARP
Methylmalonic Acidemia	Neonatal Meningitis/Encephalitis
Microcephaly	Neuronal Ceroid Lipofuscinoses
Microtia-Bilateral	Neuronal Migration Disorder
Midas syndrome	Nonketotic Hyperglycinemia
Miller (postaxial acrofacial-Dysostosis) syndrome	Noonan syndrome
	Ocular Albinism
Miller-Dieker syndrome	Oculocerebrocutaneous syndrome
Mitochondrial Disorder	Oculo-Cutaneous Albinism
Moebius syndrome	Optic Atrophy
Morquio syndrome (MPS IV)	Optic Nerve Hypoplasia

Oral-Facial-Digital syndrome Type I-VII	Pyruvate Dehydrogenase Deficiency
Osteogenesis Imperfecta Type III-IV	Radial Aplasia/Hypoplasia
Osteopetrosis (Autosomal Recessive)	Refsum Disease
Oto-Palato-Digital Syndrome Type I-II	Retinoblastoma
Pachygyria	Retinoic Acid Embryopathy
Pallister Mosaic syndrome	Retinopathy of Prematurity Stages III, IV
Pallister-Hall syndrome	Rett syndrome
Pelizaeus-Merzbacher Disease	Rickets
Pendred's syndrome	Rieger syndrome
Periventricular Leukomalacia	Roberts SC Phocomelia
Pervasive Developmental Disorder	Robinow syndrome
Peters Anomaly	Rubinstein-Taybi syndrome
Phocomelia	Sanfilippo syndrome (MPS III)
Pierre Robin Sequence	Schinzel-Giedion syndrome
Poland Sequence	Schimmelpenning syndrome (Epidermal Nevus syndrome)
Polymicrogyria	
Popliteal Pterygium syndrome	Schizencephaly
Porencephaly	Schwartz-Jampel syndrome
Prader-Willi syndrome	Seckel syndrome
Progeria	Septo-Optic Dysplasia
Propionic Acidema	Shaken Baby syndrome
Proteus syndrome	Short syndrome
Pyruvate carboxylase Deficiency	Sialidosis

Simpson-Golabi-Behmel syndrome	Townes-Brocks syndrome
Sly syndrome (MPS VII)	Treacher-Collins syndrome
Smith-Fineman-Myers syndrome	Trisomy 13
Smith-Limitz-Opitz syndrome	Trisomy 18
Smith-Magenis syndrome	Tuberous Sclerosis
Sotos syndrome	Urea Cycle Defect
Spina Bifida (Meningomyelocele)	Velocardiofacial syndrome (22q11.2 deletion)
Spinal Muscular Atrophy	
Spondyloepiphyseal Dysplasia Congenita	Wildervanck syndrome
Spondylometaphyseal Dysplasia	Walker-Warburg syndrome
Stroke	Weaver syndrome
Sturge-Weber syndrome	Wiedemann-Rautenstrauch syndrome
TAR (Thrombocytopenia-Absent Radii syndrome)	Williams syndrome
	Winchester syndrome
Thanatophoric Dysplasia	Wolf Hirschhorn syndrome
Tibial Aplasia (Hypoplasia)	Yunis-Varon syndrome
Toriello-Carey syndrome	Zellweger syndrome

(2) If a child referred to the First Steps Program was born at less than thirty-seven (37) weeks gestational age, the following shall be considered:

[~~3. Children may be determined to be developmentally delayed by professional, clinical judgement, in the event standard deviation scores are inconclusive and evaluation reveals the child has significant atypical development or quality or pattern of development, or further diagnostic evaluation is needed to address concerns related to~~

~~the five (5) areas of development. Professional judgement to determine a child to be developmentally delayed shall be obtained from an approved evaluator; or~~

~~(2) Those children who are diagnosed with physical or mental conditions which have a high probability of resulting in developmental delay and the diagnosis has been specified by KRS 200.645(10) as an established risk condition. The developmental delay shall be within one (1) of the following categories:~~

~~(a) Chromosome abnormalities associated with developmental delay;~~

~~(b) Recognizable syndromes associated with developmental delay;~~

~~(c) Abnormality in central nervous system;~~

~~(d) Neurological or neuromuscular disorders associated with developmental delay;~~

~~(e) Symptomatic intrauterine infection or neonatal central nervous system infection;~~

~~(f) Sensory impairments that result in significant visual or hearing loss, or a combination of both, interfering with the ability to respond effectively to environmental stimuli;~~

~~(g) Metabolic disease having a high likelihood of being associated with developmental delay, even with treatment;~~

~~(h) Maternal teratogen exposure at a level known to have a high risk for developmental delay;~~

~~(i) Behavioral or emotional disorders associated with extreme excesses or deficits which inhibit function;~~

~~(j) Central nervous system malignancy or trauma resulting in developmental delay.~~

~~(3) Eligibility for a premature child shall consider:]~~

(a) The chronological age of infants and toddlers who are less than twenty-four (24) months old shall be corrected to account for premature birth. The evaluator shall ensure that the instrument being used allows for the adjustment for prematurity. If it does not, another instrument shall be used. [;]

(b) Correction for prematurity is not appropriate for children born prematurely whose chronological age is twenty-four (24) months or greater.

(c) Documentation of prematurity shall include a physician's [~~physician,~~] or nurse practitioner's written [~~practitioner,~~] report of gestational age and a brief medical history.

(d) Evaluation reports on premature infants and toddlers shall include test scores calculated with the use of both corrected and chronological ages.

Section 3. Incorporation by Reference. (1) The Early, Periodic, Screening, Diagnostic and Treatment (EPSDT) Periodicity Schedule, edition, is incorporated by reference.

(2) This material may be inspected, copied or obtained, subject to applicable copyright law, at the Commission for Children with Special Health Care Needs, 982 Eastern Parkway, Louisville, Kentucky 40217, Monday through Friday, 8 a.m. to 4:30 p.m.

Section 4. The provisions of this administrative regulation shall be effective with services provided on or after September 1, 2003.

911 KAR 2:120

Reviewed:

APPROVED:

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James Gildersleve, Chair Date
Commission for Children with Special Health Care Needs

_____

Eric Friedlander, Executive Director Date
Commission for Children with Special Health Care Needs

_____

Marcia R. Morgan, Secretary Date
Cabinet for Health Services

A public hearing on this administrative regulation shall be held on May 21, 2003 at 9:00 a.m. in the Health Services Auditorium, Health Services Building, First Floor, 275 East Main Street, Frankfort, Kentucky. Individuals interested in attending this hearing shall notify this agency in writing by May 14, 2003, five workdays prior to the hearing, of their intent to attend. If no notification of intent to attend the hearing is received by that date, the hearing may be canceled. The hearing is open to the public. Any person who attends will be given an opportunity to comment on the proposed administrative regulation. A transcript of the public hearing will not be made unless a written request for a transcript is made. If you do not wish to attend the public hearing, you may submit written comments on the proposed administrative regulation. Send written notification of intent to attend the public hearing or written comments on the proposed administrative regulation to:

Jill Brown
Cabinet Regulation Coordinator
Cabinet for Health Services
Office of the Counsel
275 East Main Street - 5W-C
Frankfort, Kentucky 40621
(502) 564-7905
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